United Nations E/CN.3/2003/4

Economic and Social Council

Distr.: General
20 December 2002

Original: English

Statistical Commission
Thirty-fourth session
4-7 March 2003
Item 3 (b) of the provisional agenda*
Demographic and social statistics: health statistics

Report of the Australian Bureau of Statistics

Note by the Secretary-General

The Secretary-General has the honour to transmit to the Statistical Commission the report of the Australian Bureau of Statistics on health statistics. The report briefly describes the current Australian system of health statistics; identifies the key stakeholders and outlines the roles and responsibilities of some key agencies and committees which drive the development of the health information system in Australia; describes the major sources of data and indicates the range of frameworks which are used for organizing collection and reporting activities; and outlines Australian activities in the international arena, and identifies areas where international collaboration might be valuable in advancing the system of health statistics within countries. The Commission may wish to comment on the issues raised in paragraph 58.

* E/CN.3/2003/1.

02-75965 (E) 290103

Report of the Australian Bureau of Statistics on health statistics

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I. Introduction

1. Australia has a comprehensive and well used set of health statistics, resulting from a high level of collaboration and cooperation between several government agencies and the health-care delivery sector. In addition to describing the major sources of health data, the present report outlines the infrastructure which has been developed to improve the standardization and integration of statistical activities in Australia. Although there are many aspects of the national system in which health statisticians are keen to see further developments, Australia has a relatively rich and effective health information system.

2. The Australian health system has a diversity of arrangements for planning, funding, delivering and regulating health services, which feature a mix of private and public sector involvement. The health system is primarily driven by the first and second tiers of government, represented by the Commonwealth Department of Health and Ageing and the State and Territory health authorities.

3. Together with the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS), those government agencies play leading roles in the collection and reporting of information on health and well-being. Under the National Health Information Agreement, a national health information development plan sets out agreed national priorities for health information to be considered by the Australian Health Ministers' Advisory Council. The National Health Information Management Group (NHIMG) was established to oversee the implementation of the Agreement.

4. The Australian Bureau of Statistics is responsible for a broad range of economic and population statistics. It conducts a five-yearly population census, compiles statistics of vital events and causes of death from registration systems and conducts an extensive range of household-based surveys, including several on health and related issues. It also collects economic performance data from businesses in the health industry.

5. The Australian Institute of Health and Welfare is responsible for providing an extensive set of health and welfare statistics and information. It compiles data from systems involved in the delivery of health and welfare services, disease registers and a wide range of other sources, makes extensive use of health data collected by ABS and conducts some surveys. AIHW prepares a major report on Australia's health every two years.

6. AIHW and ABS work collaboratively to maximize the consistency, coverage and use of the data that they produce.

7. In recognition of the need for a national approach to public health and health promotion, the Commonwealth and State and Territory governments have established a national public health partnership, which is a collaborative arrangement to improve the health status of Australians, in particular those population groups most at risk. A major focus of the partnership is public health statistics.

8. The National Electronic Health Records Task Force was established in 1999 to develop a coordinated approach to electronic health records. It recommended the creation of a national health information network, Health*Connect*, which provides for systematic collection (at point of care), transfer, storage and retrieval of clinical

and demographic information in the form of event summaries. Part of the project will aim to ensure agreement among State and Commonwealth governments to work towards appropriate privacy protection for patient information. The project could offer significant statistical potential, although it is likely to be implemented on a voluntary basis, which could limit its relevance.

9. The National Health Information Standards Advisory Committee has been formed to establish nationally agreed standards across a range of areas, such as health terminologies, communication and privacy.

II. Policy drivers

A. Population health

10. The national public health information development plan 1999 recommended a number of strategies and initiatives to improve the scope, use and delivery of public health information and to develop public health information capacity in order to provide evidence to support the implementation of population health strategies or monitor their progress.

11. Of particular importance to population health will be the improved understanding of health determinants, especially for the major chronic diseases. The impact of those determinants on special needs groups, including children and youth and Aboriginal and Torres Strait Islander peoples, is receiving increased attention. Those determinants will be a target for public policy intervention.

B. Aboriginal and Torres Strait Islander health

12. Aboriginal and Torres Strait Islander health remains one of the major health issues facing Australia. Commonwealth, State and Territory governments are increasingly committed to monitoring the effectiveness of programmes and the evaluation of policies designed to improve the health status of and service delivery to Aboriginal and Torres Strait Islander peoples. This has resulted in a growing demand for high-quality, regularly reported indigenous information at a range of geographic levels, to allow for the development of performance indicators on service delivery and the consideration of social and other determinants of health, and to provide time series on health status.

C. Health system performance and labour force

13. The effective delivery of health services is dependent on the availability of suitably qualified staff. The demand for nursing staff with certain specializations has begun to exceed supply, as is the case in some medical specialties. In addition, technological and other structural change is affecting the mix of skills needed in health professions. The regional distribution of services, often dependent on the regional availability of skilled professionals, remains a major policy focus for service providers and health education planners.

14. Increased equity is a key performance goal of the health system since health status is not equally distributed across the whole community. In addition to

Aboriginal and Torres Strait Islander peoples, other groups remain vulnerable on the basis of their socio-economic status, age, geographic location or other specific circumstance, such as being incarcerated.

15. Along with concern about the health labour force, there is a continuing community debate about the pressures on the health system, whether it can be sustained in its current form and whether it can continue to produce high-quality outcomes. Existing information systems provide a wide array of information to inform that debate, but there are repeated calls for more information and more analysis based on existing information. The Australian Health Ministers' Advisory Council has established the National Health Performance Committee to develop benchmarking and reporting on health system performance.

D. Safety, quality and coordinated health care

16. Health ministers have established the Australian Council for Safety and Quality in Health Care to develop a national strategy to improve the safety and quality of health care in hospitals and other health settings; to develop a national framework for adverse event monitoring, management and prevention; and to ensure effective reporting and measurement of performance, including research and development of clinical and administrative information systems.

17. Health-care consumers, providers and funders have identified a need for greater integration of health-care service delivery to improve the continuity of care and health outcomes for individuals.

18. Evolving information and communication technologies aimed at improving the integration of care systems for consumers will create demands for monitoring a more complex mixture of services and provide opportunities for enabling information developments. A major contribution in that area should be delivered by the creation of a health information and electronic records network for Australia, Health*Connect*, designed to improve health outcomes for all Australians, while safeguarding the privacy of health consumers.

III. Major health data sources in Australia

19. Australia has a well developed statistical system based, initially, on a long-standing system of vital registrations, including registrations of deaths, from which cause-of-death data have been compiled for every year since 1907. Multiple-cause coding was introduced in 1997 to coincide with the implementation of International Statistical Classification of Diseases and Health-Related Problems, Tenth Revision (ICD-10) coding.

20. Substantial health information is also collected and disseminated from administrative records of health services, such as hospitals. The AIHW hospital morbidity database collects data on patient utilization, diagnoses, procedures and their costliness, and demographic characteristics; while the AIHW hospital establishment database collects data on expenditure, type, number and size of public hospital facilities. Similar data on private hospitals are collected by ABS in the private hospitals establishment collection.

21. Information on the composition of the health workforce is collected in the ABS Census of Population and Housing, while information on those being trained as health professionals is available from the Department of Education, Science and Training university data collections. Additional health workforce data are collected as part of regular registration processes. To report on health expenditure and source of health funding, data are compiled from a range of sources, including the private health insurance fund database, State and Territory health authorities, workers' compensation and motor vehicle third-party insurance funds.

22. Details concerning the health conditions of patients and the treatments they receive from general practitioners are collected in the "Bettering the evaluation and care in health" survey. ABS collects data from medical practitioners on demographics, qualifications, hours worked and number of patient contacts per week in the private medical practice industry collection, and collects data on employment, income and expenses on a range of health-related industries, such as dental services and optometry, in the allied health services survey.

23. Other data are registry-based, that is, a central repository is notified when certain diseases are diagnosed by health professionals. For example, cancer is a notifiable disease in all States and Territories and there is almost complete coverage of cancer incidence data. However, those collections generally collect only limited demographic data, and only for those individuals who have been in contact with health services.

24. To provide information on the Australian population as a whole and to support research into such issues as health inequalities associated with socio-demographic disadvantage, a comprehensive system of population surveys has been established in Australia to collect health and health-related data.

25. ABS undertakes a three-yearly National Health Survey and a six-yearly Survey of Disability, Ageing and Carers, using a large household sample. There are also several other population surveys, conducted by a range of institutions and agencies, which vary in content and coverage, depending on their objectives.

26. AIHW compiles data on services provided to persons with disabilities from administrative processes associated with service delivery.

27. ABS recently conducted the first of its (household) general social surveys, which collected selected data across a range of topics of social concern. Results will be available next year, and will provide a basis for analysing the interconnections between various social issues, including health and disability. ABS also recently conducted indigenous health and general social surveys to provide data for policy analysis. Health outcomes for Australia's indigenous people are significantly worse than they are for the general population, a problem that is addressed in greater detail below. However, there is considerable potential for increased coordination and harmonization across survey activities and work to that end is under way.

28. The above-mentioned components of the health information system in Australia are described in greater detail in the annex.

IV. Statistical issues

29. There are a range of issues facing the Australian health information system across the spectrum of activities, such as data development, collection, management and dissemination. Improving the cost-effectiveness of the system is an overarching issue which relates to improving the quality and relevance of data collections; increasing comparability between data collections by adopting standard definitions and methodologies; and making data more accessible to researchers while protecting the privacy and confidentiality of individual consumers and respondents. With the move to greater usage of electronic health records, there are significant community and professional concerns in such areas as privacy, ethics and data ownership. Some specific issues are outlined below.

A. Standards and classifications

30. International standards, including revisions to ICD and the new International Classification of Functioning, Disability and Health (ICF), are generally adopted quickly in official health statistics.

31. Australia will continue its efforts to develop and implement national standards and classifications. With the major proposed expansion of the national health information system into electronic health records, networks, public health, and performance and safety in the health system, there is a need to strengthen current standards infrastructure and coordination mechanisms to ensure that national "best practice" is introduced at the beginning of these processes to avoid the cost and tensions associated with aligning fragmented practices in the future.

32. Current work on the development and acceptance of national minimum data sets needs to be expanded to cover such areas as community-based services and reasons for use of hospital emergency services. The extent to which data compilers conform to these minimum collection requirements and associated standards needs to be addressed.

B. Frameworks and information development plans

33. There are a range of frameworks used within Australia to underpin the measurement of and reporting on health. Some are centred on elements that make up the Australian health system and focus on data requirements for reporting; others explore the relationships between factors that impact on health outcomes, including individual lifestyle behaviours, environmental factors and health-system responses. In some cases, the framework is complemented by a nationally agreed set of indicators for reporting, such as the national health performance framework described in more detail below.

34. In many cases, the framework is used as the basis for or in conjunction with an information development plan. Such a plan represents a national strategy for identifying priorities and improving data. Priorities may relate to streamlining and/or supplementation of collection activities, improving the use and delivery of information, increased use of standards across all activities and, most importantly, identifying the roles and responsibilities of the agencies involved.

35. Frameworks and information development plans have been developed or are being developed for such areas as public health and mental health and for population groups such as Aboriginal and Torres Strait Islander peoples; children and adolescents, and people living in rural and remote areas of Australia.

C. Management of health information

36. For health information to meet the requirements of health system managers, funders and consumers, it needs to be of sufficient quality for its purpose and to be timely and accessible by those who need it. Thus, the development and implementation of best practice guidelines, protocols and standards for data development, collection, compilation, analysis and dissemination are basic elements of a system producing quality and cost-effective information. Extensive and ongoing work has been done on data dictionaries, standard classification and data sets etc. Although much good use is made of Australia's health data, more could be done and is being planned.

D. Data linkage

37. The linkage of health data has become accepted as an invaluable tool in the monitoring of health services and health outcomes. The linkage of health records could improve the quality of care of individual clients by ensuring coordinated care across the health system. For that purpose, linkage would need to cross interfaces between sectors, such as general practitioners, hospitals, residential aged care and home-based care. From a research perspective, linked data sets provide a valuable but relatively inexpensive way of examining the movement of clients across the health-care system.

38. The techniques for linking data sets will depend on the nature of the data collection, such as administrative records or health registry records. Nevertheless, it is vital that data linkage be undertaken in such a way that client privacy is safeguarded and public concerns allayed. Confidentiality guidelines need to be developed, endorsed, implemented and enforced nationally. Ethics committee approval needs to be obtained for such procedures and for the specific research projects undertaken on the linked data sets. Some data-linkage activities in Australia are outlined below.

E. Biochemical and physical measures

39. Administrative data collections generally provide some diagnostic data, while population surveys generally provide self-reported data. A major gap in Australia's population health data is the lack of a regular survey programme to collect physical and biochemical measures. Basic physical measurements, such as height and weight, are needed to estimate the prevalence of overweight and obesity in the Australian population. Biological risk factors, such as blood pressure and cholesterol levels, are needed to provide data on priority health problems, such as diabetes, cardiovascular disease, hypertension and other chronic diseases. The Department of Health and Ageing, AIHW and ABS have been collaborating to fill that gap. A pilot survey is planned for February 2003 for the first Australian health measurement survey

(AHMS); if successful, it is proposed that a national AHMS be conducted by AIHW, in conjunction with the next ABS National Health Survey in 2004-2005.

F. Indigenous health data

40. The identification of indigenous Australians is still inadequate in many aspects. ABS has developed a standard question for identifying Aboriginal and Torres Strait Islander peoples in the census, vital registrations, administrative collections and population surveys. However, not all jurisdictions have adequate indigenous identification for vital statistics, such as mortality statistics, and coverage by hospitals varies greatly. ABS, AIHW and government agencies are working to improve coverage in all relevant data collections. Extensive consultation with indigenous people has underpinned those efforts. ABS has developed a survey strategy for Aboriginal and Torres Strait Islander peoples, acknowledging that the methodologies appropriate for indigenous people living in discrete communities will differ from those used in other national surveys. ABS aims to improve the coverage, frequency, relevance and timeliness of data collected in surveys of indigenous people.

41. As it is widely acknowledged that indigenous Australians experience worse health outcomes than any other group in the Australian population, there is considerable pressure to collect timely and relevant data on their health status. However, serious attention needs to be given to the extent that that group may be oversurveyed in the attempt to obtain data necessary for policy formulation and evaluation. To avoid that situation, effort needs to be put into such activities as maximizing the use of data currently available, improving the coordination across data-collection activities and collaborating with indigenous people to ensure that their major concerns and data requirements are addressed.

G. Gaps in population surveys

42. Despite an extensive programme of national and nationwide population surveys, Australia has some important gaps in its regular programme, including longitudinal surveys and surveys collecting detailed data in such areas as nutrition and mental health. Although a national nutrition survey was conducted in 1995 (in association with the ABS national health survey) and a survey of mental health and well-being was conducted in 1997, there are currently no plans to repeat either of those surveys on a regular basis. However, the three-yearly (household) national health surveys conducted by ABS and several State and Territory health authorities collect some basic indicators relating to dietary habits and a general measure of mental health.

V. Health information infrastructure

43. Australia has established, through such processes as the National Health Information Agreement, an infrastructure which supports the collection and dissemination of comparable data, and hence assists in providing a cost-effective information system. Some fundamental elements of that infrastructure are:

(a) Frameworks, such as the national health performance framework, to provide conceptual and operational structure;

(b) National minimum data sets (NMDs) in areas where State and Territory administrative data are integrated for national reporting;

(c) National standards and definitions that are incorporated into the national health data dictionary;

(d) The adoption of internationally endorsed health classifications, with nationally endorsed Australian modifications, where necessary.

44. The above-mentioned elements are discussed below.

A. National health performance framework

45. One key framework which guides collection and reporting activities in Australia is the national health performance framework. In 1999, Australian health ministers set up the National Health Performance Committee to report on the national health system, encompassing the acute and community health-care and public health sectors. Through a wide consultation process, the Committee has developed the framework and appropriate indicators as a basis for its reporting.

46. The Australian framework has three basic tiers of information: health status and outcomes, determinants of health and health system performance. That three-tier framework allows monitoring on how health system interventions can focus on managing determinants, such as in public health programmes, as well as those that directly relate to the treatment of diseases.

B. National minimum data sets

47. National minimum data sets have been established for mandatory collection by jurisdictions and underpin national reporting from administrative data collections relating to health service encounters. To date, approximately 20 NMDs have been established, for example an admitted patient care NMDS and public hospital establishments NMDS. Jurisdictions are responsible for the supply of data, and in most cases, AIHW compiles and disseminates national results.

C. National health data dictionary and Knowledgebase

48. Under the National Health Information Agreement, the national health data dictionary is the authoritative source of health-data definitions used in Australia, where national consistency is required. It was first published (under another name) in 1989 and is produced each year by the National Health Data Committee, a standing committee of NHIMG. It is accompanied by the web-based Knowledgebase, which is Australia's health, community services and housing metadata registry. The data dictionary and Knowledgebase have been expanded in scope over the years from administrative data collections to standard definitions for population health collections. In addition, recent activities have established the data dictionary as the repository for terms required for future electronic health records.

D. Health classifications

49. Where applicable, Australia uses international classifications, such as ICD and ICF, in administrative and population-based health collections. Within Australia, ICD-10 has been adapted by the National Centre for Classifications in Health (NCCH) to provide additional detail for morbidity coding in clinical settings. Revisions to the expanded classification, ICD-10-AM (Australian Modification), are published biennially and each revision is supported by a national education programme. In addition, NCCH has produced manuals to support the use of ICD-10-AM in such areas as community-based mental health services and early parenting centres. The development and adoption of classifications for electronic health records needs to be coordinated with World Health Organization (WHO) work in this area.

E. Geographic classifications

50. There is an increasing demand for small-area health and demographic data, particularly to assist in planning and managing health services and in monitoring health outcomes in rural and remote areas. Although there remain significant issues in data collection and confidentiality, improved data for small areas is a priority issue and would be assisted by the development of geo-coding of health facilities, providers and services, which would allow more flexible allocation of geographic classifications to health collections to assist in analysis. Current developments in the area of electronic address files should make consistent geo-coding across different data files more affordable.

F. Dissemination

51. AIHW published many reports that are available both in printed form and free of charge at www.aihw.gov.au. ABS also publishes a range of reports from its surveys that are also available at www.abs.gov.au.

VI. International activities

52. As in many fields of statistical endeavour, Australia seeks to support and assist other countries in the development of their statistics systems. For example, Australia has been involved in providing training to countries in the Asia and Pacific region on vital statistics and civil registration systems, cause-of-death certification and coding processes, and the use of mortality statistics. Although Australia's efforts are focused initially on countries in the Asia and Pacific region, Australian assistance extends well beyond those countries. For example, Australia has been involved in a training project in Romania as part of a process of health reform in that country.

53. There would appear to be scope for more organization of such assistance; to that end, Australia would wish to cooperate with the United Nations Statistics Division and WHO to maximize the effectiveness of resources and rapidly improve the availability and use of health data in other countries.

54. Australia is also an active member of the WHO Update Reference Committee, which recommends updates to ICD-10. Australia provides input to the development of international health classifications via AIHW, which is the Australian WHO collaborating centre for the family of international health classifications. That work is primarily undertaken by the National Centre for Classifications in Health (NCCH). For example, there has been considerable international interest in ICD-10-AM (Australian Modification) for use in clinical settings. In addition, NCCH has produced an abridged version of the Australian Classification of Health Interventions as a prototype international classification, specifically aimed at the needs of countries requiring a simple classification of interventions.

VII. Issues associated with international activities

55. There is a strong focus in the Australian health information system on the development and implementation of national standards that relate to the full range of statistical activities and concerns, such as classifications; conceptual frameworks to underpin data requirements and definitions; protocols for collection; privacy and confidentiality of information; and analysis and reporting. Where possible, Australian national standards align with international standards, such as those endorsed by WHO, to support Australia's international reporting obligations. In meeting that obligation, Australia is concerned about comparability issues arising from having international organizations, such as the United Nations, WHO and the Organisation for Economic Cooperation and Development (OECD), producing comparative reports on the health systems of different countries but with different frameworks. Just as Australia is working towards national standards across activities and jurisdictions, those international organizations should be working together towards international standards. A widespread collaborative effort would improve the cost-effectiveness of the international system and increase the usefulness of international comparisons. That requires leadership, by WHO in particular, in the same way that other international organizations have taken the lead in different fields of statistics. The collaborating centres could be used to support this work in a similar way they have for health classifications.

56. However, it is essential that WHO work with national statistical organizations to avoid the situation that has arisen with some projects, such as international surveys, which have used deficient statistical practices and produced data of questionable quality. WHO would be better advised to make more extensive use of existing national health data sets rather than run its own surveys.

57. There remains a huge need to develop vital statistics systems that deliver data of adequate coverage and quality in developing countries. The United Nations and WHO need to cooperate to support countries where those most basic data are not yet available.

VIII. Issues for discussion

58. The Commission may wish to discuss:

(a) Ways in which WHO could best support countries in the conduct of surveys to reliably measure and monitor changes in health status and risk factors;

(b) Mechanisms for more effective cooperation between the United Nations Statistics Division, the regional commissions, WHO and its regional collaborating centres, and specific countries, to support the development of better health-data systems and the effective analysis and use of health data in all countries, with particular emphasis on those countries where currently available data are less than adequate;

(c) The potential for establishing a city group (involving WHO and OECD) to address priority issues in the health field. The Commission may wish to discuss the potential for developing health-data sets from administrative processes;

(d) Means by which current technology and future technological advances could best be used to assist in the development of health statistical systems and the use of health data, particularly for data extracted from administrative systems.

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Annex

Health-data collections and activities in Australia *

National health surveys

1. These are the responsibility of ABS. Following a recent review of its entire household survey programme, ABS has introduced an expanded programme of household surveys, including:

(a) *National health survey (NHS) (three-yearly)*. Topics covered include demographic, socio-economic and geographic characteristics, health-status indicators, health-risk factors and health-related actions. In addition, some supplementary women's health topics, such as contraceptive use and participation in breast and cervical cancer screening, are covered. The increased frequency of NHS is supported by a funding partnership with the Commonwealth Department of Health and Ageing. Results have been published for 2001, and planning has commenced for 2004-2005;

(b) *Survey of disability, ageing and carers (six-yearly)*. This survey focuses on activity limitations and participation restrictions resulting from health conditions, and generates the Australian estimates of disability prevalence, as well as use of formal and informal services. Development of the survey to be conducted in 2003 is at an advanced stage;

(c) *General social survey (GSS) (four-yearly)*. Topics cover broad areas of social concern and include demographics, self assessed health status, housing, education, work, income, financial stress, assets and liabilities, information technology, transport, social capital, and crime;

(d) *Indigenous health survey (six-yearly)*. A relatively small supplementary survey of indigenous people was conducted in association with the 2001 NHS. It provides indicators of the health of indigenous people and enables comparisons between the health characteristics of indigenous and non-indigenous Australians. From 2004-2005, a large supplementary survey of indigenous people will be conducted with every second NHS;

(e) *Indigenous social survey (ISS) (six-yearly)*. ISS shares about half of its content with GSS and also includes additional health topics — smoking, alcohol, substance use and disability. The first survey was conducted in 2001.

2. There is a separate programme of national drug strategy household surveys, currently operated by AIHW, with funding from the Commonwealth Department of Health and Ageing, which is designed to collect information on tobacco, alcohol and illicit drug use in the community. The 2001 results have just been released.

State and territory health surveys

3. Several jurisdictions conduct health surveys, using computer-assisted telephone interviews (CATI), to provide flexible and timely information on risk factors, disease patterns and health-service use. The National CATI Health Survey Technical Reference Group has been established, under the National Public Health Partnership, to foster the use of national data standards and consistent questions and methodology across jurisdictions in CATI-based health surveys.

Administrative data

4. There are a number of major health-data collections based on administrative data. Under Australia's national health-care system, a database of medical encounters reimbursed under the Medicare system and a database of prescriptions filled under the pharmaceutical benefits scheme are maintained by the Health Insurance Commission. AIHW maintains a database of hospital episodes collected from most public and private Australian hospitals. Those data provide a rich source of information on the delivery of health services in Australia.

5. However, the data are collected for the purposes of administering health services rather than for monitoring the health system, which has two major drawbacks for attempting to use the data for monitoring health outcomes. The first is that the data are not necessarily collected in a form that is useful for health monitoring. For example, Medicare data contain no information on health condition or reason for encounter, although the AIHW hospital database provides data on each episode of care in participating hospitals, they cannot be linked to create patient records. The second major drawback relates to privacy issues since access for health monitoring may be limited because the data were not originally provided for that purpose. AIHW also compiles extensive administrative data on disability and related services.

6. Despite those drawbacks, administrative data collections provide the source for much of the data used in direct measurement of health-system performance.

Health registers

7. Australia has virtually complete registration of all deaths. Each State and Territory maintains a jurisdictional register of deaths. The causes of death for those data are coded by ABS according to the ICD-10 coding system. De-identified data sets, containing demographic characteristics and details of cause of death, can be obtained from ABS and AIHW for most analyses of mortality. In addition, AIHW holds the national death index, which contains identifying information and is used in matching against other data to establish fact and cause of death.

8. The National Cancer Statistics Clearing House, operated jointly by AIHW and the association of Australasian Cancer Registries, compiles data produced by State and Territory cancer registries. Cancer is a notifiable disease in all States and Territories, and there is almost complete coverage of cancer incidence data.

9. The Communicable Disease Network — Australia and New Zealand was established in 1990 to enhance the capacity of both countries for communicable disease surveillance and control. The Network coordinates the surveillance of communicable diseases through specialized systems, including the national notifiable diseases surveillance system, under which State and Territory health authorities submit reports of communicable disease notifications for compilation by the Commonwealth Department of Health and Ageing.

10. Other registers include:

(a) The Australian childhood immunization register at the Health Insurance Commission;

(b) The national diabetes register at AIHW;

(c) A register of cardiac surgery and coronary angioplasty at AIHW;

(d) The national coronial information system, managed by the Monash University National Centre for Coronial Information, on behalf of the Australian Coroners Society.

Data linkage projects

11. The national death index and the National Cancer Statistics Clearing House, held at AIHW, have been used by researchers outside AIHW to link their data with those death and/or cancer records, under strict confidentiality and ethical conditions, to establish fact and cause of death or to verify cancer diagnosis. AIHW has also used such linkage to establish survival after cancer diagnosis.

12. In addition, several States are establishing linked data sets with matched records from local hospital morbidity collections, mortality collections and other records. In particular, Western Australia has used health record linkage extensively for health-service analysis and research. Over the last five years, a number of projects based on linked hospital and primary-care data have been conducted under State-Commonwealth agreements.

13. AIHW, in collaboration with the Commonwealth and Western Australian Health Departments, the University of Western Australia and the Health Insurance Commission, is also developing a pilot project for linkage of hospital, medical and deaths data for patients with diabetes. That project has been approved by the AIHW Ethics Committee and is intended as a model of best practice in the use of administrative data for the production of de-identified linked data files. The project is not yet complete, but the model is already under consideration for other record linkage projects, including a linkage between BreastScreen Australia screening participation and outcome data, the AIHW cancer and deaths databases and the Health Insurance Commission's Medicare database.